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THE ALS ASSOCIATION
WESTERN PA CHAPTER

416 LINCOLN AVENUE
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INSIDE THIS ISSUE:

Chapter Update

Welcome to the newest edition of The PALS Press! For those of you who have been involved with the Chapter for several years, you'll remember that The PALS Press was a regular fixture in the Chapter's communications with PALS (Persons with ALS) and Caregivers. We're excited to bring this important newsletter back and hope that the new and improved layout and articles will better help you stay informed of important updates and highlights.

We're also excited to report that the Chapter recently held its annual meeting where Board members, volunteers and staff marked the organization's 25th anniversary and the service of extraordinary volunteers and partners over the past year. To learn more about the annual meeting and other upcoming Chapter events, see pg. 3.

What do you think?

Our hope is that this newsletter becomes an interactive tool for you to communicate with us as well as the PALS community. Please email jenni@cure4als.org or call us with questions, comments or answers to the following questions.

Q: How do you feel about being referred to as a **PALS?**
Q: How would you spend **one million dollars** for The ALS Association, if you had the opportunity?
Q: Do you have any inspirational quotes that you find helpful to you?
Q: Do you have any favorite "clean" **jokes** that always makes you laugh out loud?

We look forward to hearing from you!

In this issue we highlight PALS **Scott McGuire** (pg 2). We made sure to ask Scott the same questions we posed to you. Here are his responds:

Q: How do you feel about being referred to as a **PALS?**
A: I am indifferent to the term. It is only a descriptive; it doesn't define.

Q: How would you spend one million dollars for The ALS Association, if you had the opportunity?
A: I'd like to see half of the money used to reimburse families for their out of pocket ALS expenses and the remainder for assistive technology for our loan closet.

Q: Do you have any inspirational quotes that you find helpful to you?
A: Yes, I have three:

> "Every man dies. Not every man really lives!" - William Ross Wallace
> "Everyone faces challenges in life. Some challenges they face, others they put on the shelf to collect dust. Me?... I don't own a shelf!" - Unknown
> "I may not be the person to touch a million people, but maybe I'll touch that one that will touch a million" - Charles "Mask" Lewis

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Western Pennsylvania Chapter

PALS Spotlight: Scott McGuire

This issue's spotlight is on Scott McGuire. Scott is a husband, father, friend, social media wiz, fundraiser, inspirational hero and a PALS. He was diagnosed in November of 1997, when he was only 29 years old. Nevertheless, Scott's always been an upbeat, glass-is-half-full type of guy and remains that way to this day. And he has a lot to be upbeat about. Scott and his wife, Heidi have been married for 14 years this July and have a beautiful little boy named Gavin, who will turn five this year. He enjoys socializing with friends, working on his computer and designing various types of media, playing fantasy football and on-line poker, as well as watching Gavin grow and thrive!

Upon being diagnosed with ALS, Scott turned to his computer and the internet. As he puts it, "with time on his hands," he found that he really had an interest in communicating through various sites and applications. Social Media is a new word that is getting used quite a bit, but some of you may not be aware of what it actually means. Social Media is basically communication over the internet. Today, that consists of sites you may have heard of like Yahoo, Google, Facebook, Twitter, You Tube, LinkedIn or any of the other many sites and applications available on the internet. As Scott became more familiar with email communication with friends, he found applications that help him create photo enhancements, graphics and various greetings that help him communicate in a whole new way. For example, Scott sent out a Veteran's Day greeting through email and Facebook that contained a picture of himself and son, Gavin that resembled a cartoon but had graphics that changed colors and moved. Scott's emails are always fun and uplifting.

For those of you intimidated by working with technology and computers, you may find comfort in knowing that Scott was NOT computer savvy until his diagnosis. As Scott said, "To allow myself a creative outlet as well as validation, I used trial and error on the various devices available and the many programs and software on the market." He uses a mouth joystick with a chin switch and an eye blink device called a MyTobii. He finds these items a better option than the *sip and puff* device he used previously. (See Marie Folino's article about Tech Updates in this issue.)

Wife Heidi, son Gavin and Scott

Scott is also a Team Captain for the **Walk to Defeat ALS™**. (This year's Walk will be held on Saturday, August 7th in Johnstown and Saturday, September 11th in Pittsburgh. See next quarter's issue for more details about these important fundraising events for Patient Services.) In 2009, Scott's team, **One More Mile for Maginn** was our most successful family walk team, raising just over **$13,135.00**! When asked what he likes most about fundraising for the Walk, he said that it gives him the opportunity to reach out to all of his friends and family for assistance. His personality and hard work make such a difference to all the services that our Chapter provides. His favorite Walk Day activity is actually seeing all of those loved ones as they mingle throughout the Pittsburgh Zoo and PPG Aquarium. It really is a great and special day for everyone!

With Scott's social media work, we think he may just reach a million people himself! He definitely reaches as many as he can, in as many ways that he can. We are so grateful to Scott for his unending determination, support and inspiration!

Advocacy Update

We would like to thank everyone who contacted their Members of Congress through the past year in support of the ALS advocacy initiatives. All of your hard work paid off and we want to share two recent successes.

On December 10, 2009, the House of Representatives passes legislation that will appropriate an additional $6 million for the National ALS Registry at the Centers for Disease Control and Prevention (CDC). This is a 20% increase over last year and demonstrates that Congress has made funding for the Registry a top priority - something that would not have happened without your efforts to contact Congress and tell them why more must be done in the fight against ALS.

Also, the U.S. Senate appropriated an additional $7.5 million for the ALS Research Program at the Department of Defense (DOD), a 50% increase over last year! The funding also comes as Congress added another $2.5 million to support the Lifespan Respite Care Act, which helps to fund respite care programs in the states.

To learn more about either of these successes or other advocacy updates visit our website and click on Public Policy.

Chapter Update (continued)

Honorees included:

Founder of the Association, Rita G. Patchan was honored for her service through the creation of the *Rita G. Patchan Volunteer of the Year* Award. The 2010 *Rita G. Patchan Volunteer of the Year* Award was then given to Courtney Zydel. Courtney Zydel lost her mother three years ago to ALS when she was just 12 years old. Since then, Courtney has been a staunch advocate for The ALS Association. The *Dr. Sarah W. Wood Outstanding Advocate* Award was presented to Michael Sullivan, a current PALS. The *Monessa Tinsley-Crabb Voice of Courage* Award was presented to Joseph Hrezo, also a current PALS.

It was a great way to wrap-up 2009 and motivator for 2010. Our community of PALS, advocates and volunteers are a constant inspiration to work even harder to continue the battle against ALS.

Care Connections

The ALS Association developed a **web-based** program called "Care Connection", to assist PALS and caregivers with their day-to-day tasks. This program utilizes a network of friends, family and acquaintances to coordinate your needed support. It is a communication tool created to help with outreach assistance. The Care Coordinator (the person who tracks the needs of the household) is able to post the needs of the household on a useful calendar. This website will provide your "team" to view, sign-up and track ways to lend a hand. This helps to ensure help, coverage and keeps communication clear. The program is not meant to replace hired professional home care services. It is a way to help provide meals, shopping, companionship or the other various personal needs of our PALS and caregivers. The ALS Association of Western PA is working to start this program in our region. Look for updates!

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Clinical Trials

The ALS Clinic at Allegheny General Hospital is currently enrolling participants in a clinical trail of Ceftriaxone in Subjects with ALS. This research is being performed in multiple locations across the country. This is phase III of the clinical trial process for the drug. Dr. Sandeep Rana is heading the study at Allegeny General Hospital. Eligible participants will receive a twice daily intravenous infusion of the drug or placebo.

For more information please contact Phyllis Wanetick, RN at 412-359-8867.

Assistive Technology

Today technology has become a part of almost everyone's life as many people log onto a computer daily for both business and personal use. However, Assistive Technology can be even more important to Persons living with ALS (PALS) as devices that can assist in completing tasks that either they would not be able to do at all or allow individuals to maintain their independence through maximizing abilities.

Assistive Technology can be as advanced as the MyTobii with mouth joystick, chin and eye blink switches, such as the device that Scott is using, or low tech such as bath benches and utensil holders. Therefore, the cost can also range from thousands of dollars to less than ten dollars. Health insurances do cover the cost of some assistive technology, but not all; so it is important to check with providers to know what is covered and the amount.

There are resources available in the community to assist individuals in obtaining Assistive Technology. For example, the Pennsylvania Initiative on Assistive Technology (PIAT) is a statewide program that offers services to aid individuals in accessing Assistive Technology. One program is the Assistive Technology Lending Library which provides free short-term loans of equipment to allow individuals time to try equipment to know that it works for them before proceeding with a purchase. Another service is the Recycled Equipment and Exchange Partnership (REEP), which provides free statewide classified listing of both items for sale and items wanted by individuals. To learn more about PIATs programs and services, you can CLICK HERE.

Throughout the state, there are also PIATS's Assistive Technology Resource Centers that have Assistive Technology programs. Three Rivers Center for Independent Living (TRCIL) is one of PIAT's centers and serves Allegheny, Armstrong, Beaver, Butler, Lawrence, and Westmoreland counties. TRICIL manages the Into New Hands program which redistributes donated durable medical equipment at no cost to individuals with a disability. Also, the Pennsylvania Assistive Technology Foundation (PATF) provides cash loans for people with disabilities and older Pennsylvanians for the purchase of Assistive Technology devices, Home Modifications, adapted vehicles and vehicle modifications. For questions regarding these services or other programs call 412.371.7700 or contact Kevin, khuwe@trcil.org.

These are just a few examples of community programs and services available.

Keep in mind that our Chapter has our own Assistive Technologies as described in our Patient Services Update on page 5. Our Patient Services can direct you to the appropriate service provider as well as having a Speech & Language Pathologist, Lynn Wegrzynek, available for consultation.

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Patient Services Update

As a reminder, the ALS Association Western Pennsylvania Chapter also has the following Patient Services that will assist PALS in obtaining Assistive Technology: **The Equipment Closet** makes it possible to provide equipment free of charge for patients. Some of the equipment maintained include, but are not limited to: walkers, bath/shower equipment, other durable medical equipment. **The Speech Generating Device 80/20 Program** is a monetary grant supplementing insurance coverage. The Chapter will provide 20% of the co-pay, up to $2,000 towards the purchase of a speech generating device.

Speech Generating Devices in the ALS loan closet are distributed as a long-term loan to persons with ALS who are registered with our Chapter. Lastly, **The Norma Simon Patient Equipment Fund** will reimburse qualified patients up to $250 a year for assistive equipment or nutritional supplement. For any questions related to services contact the ALS Association Western PA Chapter at 1-800-967-9296.

ITEMS WE'RE WORKING ON FOR THE NEXT QUARTER:

- VIRTUAL SUPPORT GROUP UPDATES
- CHAPTER NEWS
- WALK TO DEFEAT ALS™

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Chapter and Community Events:

Chapter Event: **February 9, 2010: Johnstown Support Group**

Community Event: February 20-28, 2010: Prime Stage Theater presents *Tuesdays with Morrie* at The New Hazlett Theater. Special ticket prices of $10.00 each to PALS and caregivers. Call the theatre at 412.394.3353 or www.primestage.com.

Save the Date

The ALS Association will co-host a call with
The American Academy of Neurology

New ALS Practice Guidelines

This presentation has been designed to provide information to people living with ALS and their families and caregivers.

Led by four of the guidelines' authors, each a well known clinician in the field of ALS clinical care and research, the webinar will provide a practical overview and an opportunity for questions and answers.
Hosted by Sharon Matland, RN, MBA;
VP, Patient Services, The ALS Association

Thursday, February 11 at 4-5 CT (5-6 ET; 3-4 MT; 2-3 PT)

Meeting Number: 828 693 196 **Meeting Password**: PtSvcs2009
To join this meeting (Now from iPhones too!)
https://alsa.webex.com/alsa/j.php?J=828693196&PW=NMTY3NWRjNTNh
Audio attendance only: 866-699-3239

"The most beautiful things in the world are not seen nor touched. They are felt with the heart." ~Helen Keller